



Roadman for the Journey
Module
10



Description of Module 10

Wisdom from the Journey Family Matters in Early Intervention

The purpose of this module is to provide information from, for, and about families of infants and toddlers with special needs, so that service coordinators will more fully empathize with the demands that developmental disabilities place on a family. Understanding family dynamics and benefiting from the experience and wisdom that families have to offer, helps service coordinators in their efforts to partner with families.

Service coordination requires knowledge of numerous topics related to the early intervention process, but understanding the impact of disability on family relationships is imperative to effectively supporting families. Without this understanding, service coordination will fail to promote relationships that foster family competence and confidence in meeting the needs of young children with disabilities.

Service coordinators aspire to support and empathize with families on their journey; this module seeks to provide recognition for the importance of their efforts. Information highlighting fathers, grandparents, and siblings of young children with special needs is provided in this module in order to acknowledge the common and unique needs of these family members. *Wisdom from the Journey* attempts to help build a service coordinator's understanding of the day-to-day realities faced by families on their journey of hope.



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Competencies

- Has knowledge and understanding of the importance of encouraging participation from all family members in the child's program, therapy, etc.
- Has knowledge of family systems, parental reactions to handicapping conditions, and parental coping strategies.
- Has knowledge and understanding of the day-to-day realities of parenting a young child with disabilities.
- Has appreciation for the potential importance the role service coordination can play in supporting positive family relationships.
- Has knowledge and understanding of the impact on the family at the time their child receives a diagnosis of disability.
- Has knowledge and understanding of how grandparents can support families of infants and toddlers with disabilities.
- Has knowledge and understanding of the importance of the involvement of fathers in the care of the child with special needs.
- Has knowledge and understanding of the needs of siblings of infants and toddlers with disabilities.



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Contents

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- 10.2 ABC's of Special Needs
- 10.3 Life Stories from the Journey
- 10.4 Grandparenting
- 10.5 Father's Involvement
- 10.6 Siblings
- 10.7 Top Things...You wish your service coordinator knew, understood, would do, or would stop doing!
- 10.8 Souvenirs from the Journey
- 10.9 On Having to Give Bad News

Module Instructions

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Procedure/Activity	Materials	Time
Introduce the module by describing its contents. You may use the written description provided at the beginning of this guide if desired.	Description of Module 10	5 minutes
10.1 You Are the One Read the poem from PowerPoint Wisdom from the Journey – Family Matters in Early Intervention (slides 1-6). Provide a copy of 10.1a You Are the One to participant, if desired.	PowerPoint Wisdom from the Journey – Family Matters in Early Intervention (disc, web, or Blackboard) Computer with monitor or laptop or projector for viewing PowerPoint Print and provide handout of PowerPoint, if desired 10.1a You Are the One, if desired	5 minutes
10.2 ABC's of Special Needs	10.2a ABC's of Special Needs	50 minutes
The purpose of this activity is to help the participant refresh their awareness of the many demands that families of children with special needs experience.	10.2b ABC's of Special Needs Worksheet	
Twenty-six brief family scenarios are presented in handout 10.2a <i>ABC's of Special Needs.</i> Provide a copy of the handout for participant. Instruct them to read silently all scenarios. Instruct participant to select three scenarios and assuming the role of the family member, write a response to each of those three		

Procedure/Activity	Materials	Time
examples using worksheet 10.2b. Lead participant in sharing their written responses with the trainer/group. Facilitate the discussion, intended to increase empathy for families, and reinforce the importance of family- centered delivery of care. Instruct participant to place the worksheet in their portfolio.		
There are two ways to complete this portion of the training. Choose one of the following:	Video Project DOCC (Delivery of Chronic Care), VCR, TV 10.3a Life Stories from the Journey Worksheet	1 ½ hour
1. Show the video <i>Project DOCC</i> (<i>Delivery of Chronic Care</i>). From the parents in the video, service coordinators will learn how Project DOCC works to educate physicians about families of children with chronic health care needs, while refreshingltheir knowledge of the impact of diagnosis, and day-to-day caring for a child with chronic special needs.		
Following the video, instruct the participant to complete 10.3a <i>Life Stories from the Journey Worksheet</i> , show it to the trainer/supervisor for their approval, and place it in the portfolio. or		
2. Invite two local family members to meet with participant and share their responses to 10.3b Family Interview Questions. These family members should be given a copy of the questions		

Procedure/Activity	Materials	Time
prior to the training so they can prepare their responses. Select one family who has a young child with special needs and one family with an older child with special needs in order to broaden the scope of information service coordinators will hear. Remember that talking about these issues can be emotionally difficult for family members. Make every effort to make this experience as comfortable as possible for those involved.		
Following the interview, instruct the participant to complete worksheet 10.3a <i>Life Stories from the Journey Worksheet</i> , show it to the trainer/supervisor for their approval, and place it in the portfolio.		
Return to PowerPoint following the break.		
Break		15 minutes
10.4 Grandparenting Show PowerPoint Wisdom from the Journey – Family Matters in Early Intervention (slides 8-21), making the points and engaging the learner in discussion as desired.	PowerPoint Wisdom from the Journey – Family Matters in Early Intervention (disc, web, or Blackboard) Computer with monitor or laptop or projector for viewing PowerPoint	30 minutes
 Provide a copy of handout 10.5a Father's Involvement Is Important. Read the first two opening paragraphs, and then ask three participants to each read one of the fathers' stories aloud. If there are fewer than 	10.5a Father's Involvement Is Important PowerPoint Wisdom from the Journey – Family Matters in Early Intervention	35 minutes

Procedure/Activity	Materials	Time
three participants, instruct them to read the article silently. Return to PowerPoint. 2. Show PowerPoint Wisdom from the Journey – Family Matters in Early Intervention (slides 23-30), making the points and engaging the learner in discussion as desired.		
Instruct participant to read handout 10.6 What Siblings Would Like Parents and Service Providers to Know outside of training. Instruct participant to complete 10.6a Sibling Worksheet by selecting three of the twenty themes in the handout to respond to by writing why they thought this theme was significant. Instruct them to list three ways that service coordinators can involve siblings in the early intervention process. Advise participant to place the completed worksheet in the portfolio.	10.6 What Siblings Would Like Parents and Service Providers to Know 10.6a Sibling Worksheet	5 minutes
10.7 Top ThingsYou wish your service coordinator knew, understood, would do, or would stop doing! Show PowerPoint <i>Wisdom from the Journey – Family Matters in Early Intervention</i> (slides 32-45), making the points and engaging the learner in discussion as desired.	PowerPoint Wisdom from the Journey – Family Matters in Early Intervention (disc, web, or Blackboard) Computer with monitor or laptop or projector for viewing PowerPoint	20 minutes
10.8 Souvenirs from the Journey Instruct participant to complete the following reading assignments outside of training:	Copies of or access to: • 10.8a Children with Special Needs Internet Guide for Parents and Professionals http://www.state.de.us/dhss/	10 minutes

Procedure/Activity	Materials	Time
 10.8a Children with Special Needs Internet Guide for Parents and Professionals 10.8b Where Are the Parents? 10.8c Essay: Look Through the Windows of My World 10.8d To You, My Sisters 10.8e Happy Mother's Day Instruct participant to make special note of the specific disability sites in 10.8a. These sites may prove useful when information on specific disability topics is needed. Offices may choose to make a hardcopy available. 	dms/epqc/birth3/files/internet quide.pdf • 10.8b Where Are the Parents? http://www.oafccd.com/lanar k/poems/whereare.htm • 10.8c Essay: Look Through the Windows of My World http://www.users.on.net/~phi sa/Lookthroughthewindows.h tml • 10.8d To You, My Sisters http://www.arcfip.org/mysiste r.html • 10.8e Happy Mother's Day http://web.odu.edu/webroot/i nstr/ed/pmyatt.nsf/files/Happ y_Mothers_Day.pdf	
10.9 On Having to Give Bad News	PowerPoint On Having to Give Bad News (disc, web, or	5 minutes
Show PowerPoint On Having to Give Bad News.	Blackboard)	
	Computer with monitor or laptop or projector for viewing PowerPoint	Total time= 4 ½ hours



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Bibliography and Resources

AARP. *Grandparents Raising Grandchildren: Where to Find Help.* [Online] Available: http://www.aarp.org/confacts/programs/grandraising.html Retrieved: 2004, July 23].

Borgman, L. Knight Ridder News Service. *Happy Mother's Day.* [Online]
Available:
http://web.odu.edu/webroot/instr/ed/pmyatt.nsf/files/Happy_Mothers_Day.pdf [Retrieved: 2004, August 15].

Children with Special Needs Internet Guide for Parents and Professionals. 2002. Delaware Department of Health & Social Services. Birth to Three Early intervention System. Updated and revised for the Birth to Three Early intervention System by Connie Luciani 2001. [Online] Available: http://www.state.de.us/dhss/dms/epqc/birth3/files/internetguide.pdf Retrieved: 2004, August 15].

Fialka, J. (1997, 2001). *It Matters: Lessons from my son. On Having to Give Bad News.* Huntington Woods, MI.

Findell, et. al. 1996. Parents, Grandparents can Work Together to Assist Families of Children with Disabilities. Used with permission from PACER Center Inc. Minneapolis, MN. [Online] Available: www.pacer.org [Retrieved: 2004, July 23].

Higgins, M. To You, My Sisters. [Online] Available: http://www.arcfip.org/mysister.html [Retrieved: 2004, August 15].

Linkhorn, Pat. 2001. Essay: Look Through the Windows of My World. [Online] Available: http://www.users.on.net/~phisa/Lookthroughthewindows.html [Retrieved: 2004, August 15].

- PACER Center Inc. 2000. *Tips for Fathers of Children with Disabilities*. Used with permission from PACER Center, Inc. Minneapolis, MN. [Online] Available: www.pacer.org [Retrieved: 2004, August 1].
- Patricia, B. 2000. *Father's Involvement is Important.* Used with permission from PACER Center Inc. Reprinted from PACER Center's Early Childhood Connection, Summer 1999. Minneapolis, MN. [Online] Available: www.pacer.org [Retrieved: 2004, August 6].
- Stuyvesant, Sue. Where Are the Parents?. [Online] Available: http://www.oafccd.com/lanark/poems/whereare.htm [Retrieved: 2004, August 15].
- The Sibling Support Project of the Arc of the United States. What Siblings Would Like Parents and Service Providers to Know. [Online] Available: www.thearc.org/siblingsupport/pub-whattoknow [Retrieved: 2004, August 6].